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SUPPORTING YOUNG PEOPLE WITH PSYCHOSIS IN THE COMMUNITY: AN ICT ENABLED RELAPSE PREVENTION TOOL

Research in Progress

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Abstract

Psychotic disorders are the most disabling of all mental illnesses and place a heavy demand on limited mental health services. Consequently, this research aims to develop novel approaches to care which are less demanding of public resources. This research-in-progress is based in an innovative youth mental health service in Australia. It presents a model for a web-based platform which provides support for relapse prevention in young people with first-episode psychosis (FEP).

This study combines Information Systems and Psychology theory and research to develop an advanced web-based interactive psychosocial intervention for relapse prevention and recovery in FEP. While web-based applications to support schizophrenia, depression and anxiety have been researched such approaches have not been applied to the problem of relapse prevention in young people with FEP.

The research uses focus groups to study case managers, clients of the support organisation and usability experts to inform an initial prototype which has then been presented to a group of clients for evaluation. It concludes that an intervention based on intelligent technologies which combine social networking and web-based treatment to promote independent home based care would best suit the characteristics of the target group and should be tested in large-scale in the community.

Key words: Technology, Psycho-social intervention.

1 INTRODUCTION

Psychotic disorders are amongst the most distressing and severely disabling of all mental health problems. Findings from the World Health Organization's Global Burden of Disease study indicated that schizophrenia alone accounts for 1.1% of the total disability-adjusted life years (DALYs) and 2.8% of years lived with disability (YLDs) (Rossler, Salize et al. 2005). For the majority of affected individuals, psychosis results in great personal suffering. The combined economic and social costs of psychotic illnesses place them among the world's top ten causes of disability-adjusted life-years (Murray CJL, Lopez AD et al. 1996).

Most of the cost associated with schizophrenia can be attributed to hospitalizations following relapse (Rossler, Salize et al. 2005). Over the past 15 years, early identification and intervention for psychosis has emerged as an international focus of research and clinical service delivery (McGorry 2005). This approach is underpinned by findings that delay in providing effective interventions may result in high rates of relapse and poorer long-term clinical and psychosocial outcomes (Marshall, Lewis et al. 2005). In addition, research has shown that most clinical and psychosocial deterioration in psychosis occurs in the early phase of the illness, suggesting that interventions should target this critical period (Birchwood, Todd et al. 1998). Early interventions have been argued to be more effective as well as more benign (McGorry 2007) and provide greater long-term positive healthcare outcomes.

Given this background, it is not surprising that early psychosis treatment guidelines include relapse prevention as a major element of interventions for first-episode psychosis (FEP) (Royal ANZ College of Psychiatry report, 2005). Studies have shown that after their first psychotic episode, most patients relapse within 2-5 years despite some evidence for the benefits of prophylactic medication in reducing relapse (Gleeson, Cotton et al. 2009). Thus, it is imperative that new ways are found to keep young people with FEP engaged in treatment to reduce relapse and improve preventive benefits.

The Internet and mobile technologies have the potential to deliver cost-effective, non-stigmatizing, always-available interventions to young people, including those who do not currently seek or receive on-going help for psychosis. Internet-based interventions have already been shown to provide effective treatment for disorders such as depression and anxiety (Griffiths and Christensen 2007). In addition, evidence suggests that web-based interventions may reduce stigmatizing attitudes to mental disorders (Griffiths, Christensen et al. 2004). However online interventions have not yet been employed and tested for the treatment of first-episode psychosis. While many governments worldwide are keen to support on-line mental health initiatives (Stark 2010), to be effective, these need to be designed taking into account the specific characteristics of this target group.

This paper describes work in progress to design an Internet-based intervention which has the potential for significant outcomes in providing support services in the home for patients with FEP. It addresses the problem of severe workforce and resource shortages in the health sector and can aid in reducing the need to call on specialist services. To develop this intervention, this research first examines the characteristics of patients suffering from first-episode psychosis (FEP) then uses Information Systems (IS) theory and literature to propose ways in which information and communication technologies (ICT) may support relapse prevention. Using this information as well as the findings from focus groups with patients and their case managers and with an expert usability panel, we propose a design for an internet based intervention. Finally we present results from initial user testing.

2 CHARACTERISTICS OF PATIENTS WITH FEP

Patients with FEP are commonly characterised in the following way:

Recovery Style: Integration and sealing over are two recovery styles that are typically observed in patients with psychiatric illnesses (McGlashan 1987). Patients who use an integrative style incorporate psychosis (or other illness) into their wider life experience. Integrators are more open to discussing

their symptoms and understanding the risk factors that may exacerbate their symptoms, and as such, they have better clinical outcomes (McGlashan 1987). In contrast, patients who tend to seal over may deny they have an illness, hoping it was a one-off experience, and resist treatment because of the stigma associated with their mental illness (McGlashan 1987).

Stigma: Many people who would benefit from mental health services opt not to pursue them or fail to fully participate once they have begun and one of the reasons is stigma; namely, to avoid the label of mental illness and the harm it brings (Corrigan 2004; Tsang 2006). Psychiatric stigma has been singled out as the primary obstacle to recovery from severe mental illness (Corrigan,2004, Frese, 1993; Wahl & Harman, 1989). Stigmatised mental health consumers are more likely to avoid social interaction with people outside family (Holmes and River 1998) and avoid seeking help from psychiatric services (Dinos 2004).

Cognitive Deficits: The severity and pattern of cognitive deficits in epidemiological cohorts of patients with FEP is unclear, and deficits vary between individuals (González-Blanch, Crespo-Facorro et al. 2007). It was found that the speed of processing was severely impaired in first-episode schizophrenia spectrum disorders (González-Blanch, Crespo-Facorro et al. 2007) and this could mediate a broader diversity of cognitive deficits (Rodríguez-Sánchez 2007).

Engagement Issues: Patients with psychotic illness are often difficult to engage. Additionally, whereas many adults are comfortable with direct face-to-face dialogue, this is often not the case with young people. Many teenagers are private and self-conscious and often react confrontationally or not at all to direct dialogue with a therapist (Coyle 2007).

Responsiveness to Treatment: Studies have shown that FEP patients are more responsive to treatment compared to patients with more enduring forms of psychosis, thus we need to develop specific interventions for this phase of the disorder. One such intervention is a multi-modal individual and family relapse prevention therapy (RPT) underpinned by a CBT framework that has been found to significantly reduce relapse in clinically remitted FEP patients (Gleeson, Cotton et al. 2009).

3 FEP CHARACTERISTICS AND TECHNOLOGY USE

In designing an ICT based intervention that takes account of these characteristics of FEP patients, the following significant issues need to be considered:

An ICT-based intervention needs to provide for patients with both recovery styles. Patients with an integrative style would be more receptive to participating in a mental health intervention, and more likely to be interested in trying a new approach with information and communication technologies (ICTs) to learn more about their illness. On the other hand information may need to be delivered in a less challenging way to patients who are less insightful about their condition (Alvarez-Jiménez, Gleeson et al. 2009).

For a less insightful patient, a multi-leaved application may be required that leads them to a part of the application that focuses on symptoms that the patient was able to acknowledge, such as depression, for example, rather than on the psychosis. The application would need to be designed in such a way that these different pathways were possible.

To deal with the problem of stigma, the application should provide an alternative for patients wishing to avoid interaction with traditional psychiatric services.

Patients with FEP may be deterred by complicated ICTs and fatigued by activities that require prolonged concentration or commitment. Consequently, an ICT based design that is not difficult to learn or use, including uncomplicated material and instructions, is most appropriate. The ICT must be simple enough to be used by patients exhibiting greater cognitive deficits, but not be so simple that it fails to attract and engage a more cognitively capable patient.

Given the general enthusiasm of many young people for modern technology, there is potential for ICTs to play an effective role in interventions for young people with FEP (Coyle, Doherty et al. 2007). With respect to engagement, the adolescent population in general is particularly comfortable interacting within the computer environment, and many young people would sometimes rather interact with a computer than have to talk to a therapist (Abeles, Verduyn et al. 2009).

4 PREVIOUS RESEARCH ON ICTS IN MENTAL HEALTH

Various ICTs have been tested in mental health interventions, including the treatment and monitoring of psychosis. In some instances, ICTs have been used as an adjunct to traditional face-to-face therapy, and in others, the computer has delivered almost the entire psychotherapeutic treatment (Coyle, Doherty et al. 2007).

The use of mobile phone text messaging has been shown to be an effective form of asynchronous computer mediated communication in the treatment and monitoring of mental disorders, including psychosis (Bauer, Percevic et al. 2003; Spaniel, Vohlídka et al. 2008).

One particular intervention, ITAREPS (Information Technology Aided Relapse Prevention Programme in Schizophrenia) employed mobile phone-based weekly remote patient monitoring and disease management in schizophrenia and other psychotic disorders (Spaniel, Vohlídka et al. 2008).In previous studies timely review of patient mental health status with close to real-time feedback has been shown as a critical success factor in the management of psychosis (Herz 2000) and was the rationale behind ITAREPS.

E-mail is the most frequently used method of electronic communication between patients and health care providers (Castelnuovo, Gaggioli et al. 2003). An advantage with email is that the patient can always re-read, rehearse, and reinforce the solutions and resolutions contained in the correspondence (Rochlen, Zack et al. 2004). Yager (2001) used e-mail as a therapeutic adjunct in the outpatient treatment of anorexia nervosa. Results of this study showed a clinical improvement for all patients in the experimental group. Furthermore, patients accepted the rationale of using e-mail as a therapeutic adjunct, and they considered it helpful (Yager 2001).

However, the use of e-mail can have drawbacks. For example, unwanted disclosures or inappropriate or excessive use of email may result in a feeling of lack of privacy and boundaries for both the patient and clinician. Clinician failure to respond in a timely and adequate fashion can be troubling for patients. There is also a risk of the clinician failing to recognise urgent and troubled communications meriting phone and/or face-to-face contact (Murdoch 2000).

Online self-help groups include bulletin boards, chat rooms, and news and discussion groups operated within health-related Web pages, electronic mailing lists and other electronic forums focussed on the sharing and solving of psychological disturbances (Humphreys, Winzelberg et al. 2000). These may be unstructured discussion groups or may be led by an individual, usually a non-professional, who shares the problem that the group addresses (Castelnuovo, Gaggioli et al. 2003). The efficacy and effectiveness of online self-help groups has been supported in studies of eating disorders (Celio, Winzelberg et al. 2000) and depression (Dyer and Thompson 2000). The principle of the self-help group is that members are encouraged to share experiences and exchange emotional support to alleviate a sense of isolation and solve common problems (Castelnuovo, Gaggioli et al. 2003). The evidence for the use of forums has been positive (Houston 2002), especially for online self-help groups hosted by a mental health professional (Hsiung 2000).

An advantage of the approaches discussed above is the disinhibiting effect of online communication. In the context of online therapy, disinhibition can encourage therapeutic expression and self-reflection, although it can also be a cause of antisocial on-line behaviour (Rochlen, Zack et al. 2004).

Psycho-education, such as used in online CBT, has been shown to affect a person's recovery style, and is an important aspect of mental health interventions (Thompson, McGorry et al. 2003). Previous

interventions and treatment of psychosis have involved various forms of psycho-education, with the material being delivered either using face-to-face contact, through brochures, as well as using ICTs, such as CD-ROMs or web-pages. Computer-based psycho-education via a CD-ROM (Jones 2001; Walker 2006) can be as effective as traditional face-to-face or paper-based methods. Psycho-education delivered via a website is effective when patients spend enough time on the website to complete required modules or read the right amount of information. One draw back of on-line treatments such as online CBT is that many patients do not persist in viewing all the available material when it is offered on a website and some sites such Moodgym have high dropout rates (Christensen, Griffiths et al. 2006).

There has been no previous research on the link between ICT-based social networking and psychosis. However, examining the general literature on social networking leads to some tentative conclusions. Research suggests that young people are keen to use such sites and are sufficiently attracted to them that usage may counteract disengagement with CBT. Social networking is an effective tool in supporting pre-existing relationships (Boyd and Ellison 2007) and users of sites such as Facebook have been found to be willing to share information on the site and have a high level of trust in the maintenance of their privacy by the site providers (Dwyer, Hiltz et al. 2007). Studies examining the connection between adolescent well-being and on-line behaviour support the idea that on-line behaviour can stimulate well being by reinforcing existing relationships (Valkenburg 2007).

5 IMPLEMENTATION GUIDELINES

The research summarized above suggests the following guidelines for ICT-based interventions for FEP, and have been implemented in our initial prototype:

- 1. Interventions need to cater for clients with both high and low insight, and use psycho-education to improve insight.
- 2. Interventions should be fun and engaging.
- 3. Interventions should be designed in ways that are simple to navigate and use clear instructions to accommodate cognitive deficits
- 4. Interventions need to use close to real-time feedback, whether by sms or email or other electronic message, to reinforce that there is a caring clinician involved in the intervention and prevent the client feeling he is dealing with an automated environment.
- 5. The intervention should provide group support from clients with similar experiences. Social networking is the most recommended of the available options as it is the most popular of those currently in use by the target adolescent group.
- 6. Any on-line therapy would need to retain some of the proven features of face-to-face therapy such as necessitating some commitment to completing on-line treatments in logical stages, and would benefit from harnessing the previous success of CBT in treating FEP.

Thus what is recommended is an intervention which initially assesses the insight level of the client, then directs them to an appropriately focussed on-line CBT based application. This should require some commitment from participants, and not involve excessive written communication. The application should work in tandem with group social networking features, both for therapeutic purposes and to induce participation and interest in the programme. The program must be supported by a "live" caseworker who can monitor for progress and risks.

6 METHODS

Following the guidelines developed above, we conducted four stages of research and development:

Stage One: Focus groups of prospective system users. One focus group was made up of 6 clients of a youth mental health service who had all been sufferers of FEP. They were self-selected members of a team of experienced clients which performs an advocacy function representing clients from the centre. The focus was on what type of functionality and support, if any, they would like to experience in a phone-based or internet enabled psychological intervention.

The other focus group consisted of 6 case managers of these clients. A focus was on how much the intervention could facilitate, replicate, or disrupt staff-client communication.

Stage Two: An initial Web based prototype was developed for testing.

Stage Three: An expert review panel comprising researchers, web designers and developers examined the prototype interface for useability issues and system functionality. Suggestions from the expert panel were incorporated in the prototype. Client representatives were revisited to test their responses to the revised prototype.

Stage Four: A final prototype based on all inputs from both the literature review and stages 1-3 has been developed in anticipation of a more significant sized roll-out to FEP clients.

7 FINDINGS

- **Stage One Results:** The outputs of these focus groups were coded and analysed using Nvivo. The client focus group raised these issues:
- 1. Most of this sample had internet at home which they were able to use it in private. (This was considered an essential requirement for use of such an intervention and an appropriate funding target for governments seeking to move treatments away from more expensive face to face care.)
- 2. While already mobile phone users, there was little enthusiasm for SMS based systems, partly because of cost (they're always out of phone credit), and especially if the messages they receive are automated rather than of human origin. There was little enthusiasm for "motivational messages". Some also said that when in a paranoid state SMS could be frightening.
- It is preferred that the style and timing of access should be chosen by the client. There were concerns about using ICT in certain frames of mind or at certain stages of psychosis and recovery during intense psychosis computers can be difficult or frightening. This may be a barrier to system use. Management of the system by an active case-worker was considered important.
- 4. Access to patient records through the proposed site needs to be secure and privacy taken into consideration.
- 5. CBT needs to be incorporated in an appealing way.
- 6. Social networking is important and Facebook is significant in clients' lives. Clients felt that some of the best advice they had received during clinical programs came from fellow clients.
- 7. Cost of hardware and access needs to be low
- 8. Clients were anxious about systems that required them to fill out questionnaires. They related situations when questionnaires made them feel worse and focus negatively on their condition.

The client group envisaged a web-based system with three functions:

- 1. Asynchronous, ongoing communication with centre staff. The system should keep records of interaction and appropriate staff should be able to see the record, but not other clients.
- 2. Client-to-client social networking. This should be like Facebook, but completely separate from it. They recognized that malicious messages could be sent from one client to another, and suggested that the system be moderated, though not censored.

3. While many said they did not enjoy CBT, they recognised the value of it and felt it should be part of the intervention.

The case manager focus-group verified the client findings but raised a number of other concerns:

- 1. Case managers were concerned that different types of clients, such as high or low functioning may be more or less capable of using the technology. Case managers also felt that an effective intervention would require clients to be categorised by level of insight about their symptoms.
- 2. Case managers were concerned about the impact of the intervention on their workload. Case workers already make use of voice calls and SMS for administrative and clinical functions, but rarely use email to interact with clients and were concerned about finding time to respond to online messages.
- 3. Case managers warned that the high uptake of the Internet and technologies such as iPhone among young people in general may not be as high among youth with mental health conditions.
- 4. Case managers were concerned about poor IT infrastructure in publicly funded faculties. They said they had "the slowest computers on earth" and had been provided with so few mobile phones that they have to share them. This made contact with clients difficult as clients are anxious about not knowing which specific case manager will receive a message.
- 5. Case managers were concerned whether online interaction could be as effective as face-toface, and felt that some clients needed to be "dragged out of the house".
- **Stage Three Results:** We took the results of earlier stages and developed an initial working prototype. The expert usability review panel conducted standard software usability tests (Rubin 2008). Taking the inputs from the expert panel we redeveloped the interface. Then we took this reworked prototype back to the Platform team user group. Overall the response to the system was cautiously optimistic with the following additional suggestions made:
 - 1. The aspects of the system that require users to "talk about themselves" need to be designed to account for participants not being inclined to self reflect in a positive manner. It may be therapeutic for users to be able to upload their own artwork or creative endeavours.
 - 2. The system needs to bring users into the world, not allow them to hide within an institution or organisation based social network. This could be done possibly through events advertised by staff or sections on the site that had articles and materials of general interest to the user group.
 - 3. But users would be motivated to use an online intervention if it presented them with the ability to connect with their friends at times when they were unwilling to go out.

8 FINAL PROPOSAL

Informed by the combined findings described above, the proposal is for a web-based application which combines psychosocial education in the form of CBT modules with a social networking function supported by an on-line caseworker. The initial intention is to rollout the design for use on PCs, though we have also developed a prototype for smartphones.

The social networking subsystem is not restricted to messaging but includes structured interaction around problem-solving tasks. It is hoped also that the social networking facility might help to ameliorate social isolation.

The application will first use a simple questionnaire to categorise patients according to levels of insight. Low insight patients will then complete a module which is designed to increase insight and make it possible to benefit from later modules and make participation worthwhile.

We addressed case-manager concerns about the replacement of face-to-face counselling by emphasizing that at present most FEP clients are only given 18 months to 2 years of face-to-face support within a specialised FEP service. The new intervention is designed to provide further support at home after this period. However, on-line case worker support for the intervention will still be a limited resource and it is considered that funds will be best spent on supporting high insight patients who have a greater likelihood of success. As demonstrated by the client focus group, patients with higher insight were more likely to see the value of doing CBT and to be likely to complete the modules.

The system presents clients with a front page where both a social networking option and CBT modules are available. It will have an attractive, "youthful" visual design.. Principles of interface design which encourage engagement and ease of use will be applied (Gill 2008). With encouragement from the online case worker, clients will progress through CBT modules in order. Both research on the use of social networking (Dwyer, Hiltz et al. 2007; Joinson 2008) and data from the client focus group lead us to believe that the attraction of the social networking function will encourage initial use of the site.

Users will initially have had face-to-face treatment at a centre and will be acquainted with other site users and used to engaging with groups of other young people who share their condition. It is hoped that these factors will overcome the high rates of attrition that have been evidenced on CBT-only sites (Christensen, Griffiths et al. 2006).

Caseworkers will monitor social networking and deal with any negative effects of disinhibition, as well as monitoring for other signs of client risk. The system will keep track of which CBT modules have been completed and the caseworker will be able to see the current status of each client as well as the details of how the client completed the modules. Questionnaires are broken up three to five questions at a time to overcome resistance to this type of presentation and keep patients onsite.

Patients will be able to progress sequentially through 14 CBT modules which are selected for their proven effectiveness with FEP clients (Alvarez-Jimenez, Wade et al. 2008). Upon completing a module there will be an inbuilt delay of approximately two days before a subsequent module can be accessed, which is deemed therapeutically appropriate (Gleeson, Cotton et al. 2009).

Once the initial engagement questionnaires have been completed clients will be presented with a named, personalised letter, setting out their aims, goals and achievements to date. The system will also provide warnings and progress reports to case managers so that they can intervene if necessary, following the successful ITAREPS intervention (Spaniel, Vohdilka et al, 2008).

9 CONCLUSION

ICTs have the potential to greatly assist treatment and prevent relapse in patients with FEP when appropriately designed to take account of the characteristics of patients with the condition, the specific features of individual technologies and common patterns of usage.

This project has surveyed the literature on FEP and on previous ICT-enabled psychological interventions, and conducted focus groups with potential users, case managers and usability experts. It has then produced and tested a prototype novel, FEP-focussed Internet-based intervention for use by clients at home and found initial support from the target group.

Both hardware and broadband services are becoming cheaper and more readily accessible over time: the intervention can be adapted to changes in affordability and availability of resources, such as smartphones that provide web-access. The small test sample has been a limitation of the study but in ongoing research, the proposed design will be tested on a significant large sample of FEP clients.

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